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November 28, 2011

Ms. Megan Thompson
Legislative Correspondent
The Honorable John Kerry
U.S. Senate
218 Russell Senate Office Building
Washington, D.C. 20515

Dear Ms. Thompson:

Thank you for taking the time to meet with us on October 12 on behalf of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) regarding health care coverage of medical foods for infants and children with diseases of the gastrointestinal system and liver.

We are very grateful for Senator Kerry's leadership on this important issue. However, as we discussed, the "Medical Foods Equity Act," (S. 311) would fail to cover many of the diseases we treat because the Advisory Committee on Heritable Disorders in Newborns and Children is limited to advising the Secretary of Health and Human Services (HHS) on heritable disorders. Many diseases of the gastrointestinal system and liver frequently require medical foods, including expensive vitamin formulations, but they are not inherited genetic disorders and therefore would not fit within the jurisdiction of the Advisory Committee.

Diseases of the digestive system for which medical foods constitute the prescribed medical treatment also include:

- chronic gastrointestinal diseases, complicated by malabsorption and malnutrition (e.g. short bowel syndrome/intestinal failure, Crohn's disease, chronic pancreatitis);
- chronic serious liver disease (e.g. biliary atresia, genetic cholestatic syndromes); and
- chronic allergic syndromes (e.g. eosinophilic esophagitis, food allergies and allergic gastroenteritis).

All of these conditions have clear medical definitions that would allow for appropriate use of and qualification for medical food benefits, thus avoiding broad overuse of the benefit.

Also as we discussed, many health plans will cover medical foods, but only after a surgical tube has been placed into a child's stomach to administer the food, even if the child could take these foods by mouth. This practice is not only more costly to the health care system, but it is fundamentally unfair to patients. Enteral administration of medical foods by tube feeding should only be used in situations where the child is unable to consume sufficient quantities of needed foods orally. Enteral administration through devices can not only have associated potential complications, but it also can be

cumbersome to the family and the patient.

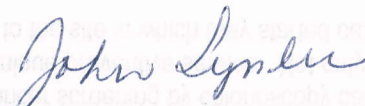
Section 1302 of the Patient Protection and Affordable Care Act requires the Secretary of HHS to define essential health benefits that must be covered by qualified health plans offering coverage through state Health Benefit Exchanges. NASPGHAN strongly believes that medical foods should be defined as an essential health benefit for infants and children. Medical foods prescribed by physicians are often needed to foster normal growth and development that are unique to childhood. In some cases, medical foods are prescribed to prevent serious disability, or even death. We hope that Senator Kerry will issue his support for the inclusion of medical foods in the definition of essential health benefits for infants and children with diseases or conditions that require special dietary intervention, including, but not limited to, inheritable metabolic diseases.

A national coverage policy for medical foods is a top priority for NASPGHAN. We hope that you will look to NASPGHAN as a resource on this issue as the discussion of essential health benefits progresses. Should you have any questions, please feel free to contact Camille Bonta, NASPGHAN's Washington representative, at (202) 320-3658 or cbonta@summithealthconsulting.com.

Sincerely,



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